



**NHS England consultation
Investing in specialised services
April 2015**

Response reference: ANON-TTXA-1KMZ-4

Consultation questions and responses:

Question 1

Do you have any comments on the principles that we have proposed to underpin the process for making investment decisions about specialised services?

Reference clause Section 19 (i)

'NHS England will: a) follow its normal good practice in making prioritisation decisions in a transparent way, documenting the outcomes at all stages of the process;'

PID UK would welcome greater transparency in all processes, structures and appointments. This should be backed up by up to date information being posted on the NHS website. As a patient organisation it is challenging to explain the workings of the various structures to our community, how decisions are made or by whom, and why decisions are delayed. Greater transparency and accountability would help. We have particular concern about the delay in development of important policies that impact on patient care and would welcome timelines for development alongside details of progress made. Periodic audits should be in place to ensure there is no stalling of activity. It has been frustrating and disheartening as a member of two CRGs to watch the many efforts of the group fall into a 'black hole', not be recognised or sanctioned. This has led to an erosion of the goodwill of those who give up their time voluntarily to sit on CRGs.

Reference clause 'b) involve the diversity of stakeholders including the public in the development of proposals and take appropriate account of their views;'

PID UK would welcome greater emphasis on meaningful patient public engagement and that means from the start of the policy development process and not at the end stage when it appears decisions have already been taken.

Reference clause (ii) ‘Does the treatment or intervention work?’

NHS England will normally only accord priority to treatments or interventions where: a) there is adequate and clinically reliable evidence to demonstrate clinical effectiveness; b) there is a deliverable and measurable benefit to patients; and,

These criteria need to take into account the paucity of clinical evidence for people affected by rare conditions and for which expert opinion is largely relied upon. It would be wrong to penalise patients with rare conditions who fall under specialised services at the expense of more common conditions where the evidence is more readily available.

PID UK would like to see definitions of ‘adequate’ and ‘clinically reliable evidence’ and clinical effectiveness’.

Reference clause ‘A deliverable and measurable benefit to patients’

PID UK would like to see a definition of this phrase and the parameters by which it will be measured. For example will it include holistic measures such as a reduced burden on carers, social care and benefits system?

Reference clause c) ‘they offer equal or greater benefit than other forms of care already in NHS use. NHS England will not confer higher priority to a treatment or intervention solely on the basis it is the only one available.’

Is it unclear how this would work and what will be used as a benchmark for comparison?
Greater clarity is needed.

Reference clause (iii) ‘Is the treatment or intervention fair and equitable? NHS England: a) may accord priority to treatments or interventions for rare conditions even where there is limited published evidence on clinical effectiveness, recognising that the rarity of the condition may make such data unavailable;’

PID UK welcomes this principle that is in keeping with the UK Strategy for Rare Diseases. It is essential that the decision making process involves someone who has the appropriate expertise for the condition or health complication. It may be also possible to streamline decision making across a range of rare conditions that share similar health complications and that require medication for that problem.

Reference clause b) ‘will only prioritise treatments or interventions where these can be offered to all patients within the same patient group (other than for clinical contra-indication).’

Primary immunodeficiencies represent a wide spectrum of disorders and the associated

health complications vary considerably from patient to patient, for example, some patients may have autoimmune complications and others may not. PID UK are concerned that this clause as currently worded is a way of denying treatment to some patients who might need specific treatments or interventions. Clinicians should be able to offer treatments according to clinical need and that meet agreed clinical criteria. This clause therefore needs rewording.

Reference clause d) *'will take into account evidence of the impact of any prioritisation decisions on the wider health and care system, including societal impact.'*

PID UK welcomes this recognition that decisions need to take into account this broader holistic view. New medicines and interventions can improve the quality of life and health of patients, this in turn impacts on their family, their ability to work and to add to society.

Reference clause e) *'will seek to advance parity between mental and physical health.'*

PID UK supports this principle. Having a long-term chronic illness seriously impacts on the mental well being of those affected. Evidence suggests that tackling any associated depression and anxiety through counselling and cognitive behavioural therapies can improve the quality of life of patients and may help save money to the NHS through better drug compliance, self-management resulting in fewer hospital admissions.

Reference clause (iv) *'Is the treatment or intervention a reasonable cost to the public?'*

Greater clarity is needed as to what this means. This also needs to be looked at holistically combining principles (ii), (iv) and (d).

Reference clause *'NHS England will: a) prioritise those treatments and interventions that demonstrate the greatest value for money; and*

Greater clarification of what 'value for money' means and what parameters will be used to assess this is required. This is essential for transparency for patients and patient groups so that they understand the decisions being made and for them to be able influence the 'value' factor.

Reference clause b) *'only commission for those prioritised treatments and interventions that are affordable within its relevant budget,'*

This is a critical clause for patients with PID who fall under specialised commissioning and its meaning and implications are far from clear.

What is a 'relevant budget' and at what level of organisational structure would this happen? Embarrassingly for NHS England, experience has exposed the difficulty in assessing the activity and cost of specialised care due to poor coding systems and IT infrastructure so how

would this be set?

It is evident that the relevant budget for many disorders including PID has been based on the outturn costs prior to specialist commissioning, rather than the budgetary needs of the service e.g. in ultra rare conditions. The commissioners should look at high tariff services and determine if more equitable budgets could be applied to those that were historically lower, this would help improve the quality and safety of services that are currently resource constrained due to income.

Reference clause *'and those that enable resources to be released for reinvestment.'*

PID UK is concerned that this linkage will skew the way decisions are made for patients care and that it flies in the face of making judgments based on clinical need and cost. Cheaper and less effective treatments might be prioritised because they release funds but this could be at the expense of other high cost and urgently needed treatments for patients becoming a low priority. Furthermore this may act to stifle innovations that may benefit patients and become a disincentive to investment in developing orphan medicines.

PID UK supports the best use of budgets and taxpayers' money but cannot support this statement b) because of these implications.

Question 2

Are there any other principles that you think NHS England should adopt as part of its process for making investment decisions about specialised services?

Yes. The introduction of IFR policy, which was largely designed to restrict access to specialist medicines, has meant that patients are waiting or being denied the treatment they need without interim measures being put in place. This is not acceptable and is causing real harm.

The stagnant policy development process has exacerbated this. These delays are seriously impacting on patient care and well being and this needs to be rectified as a matter of priority. Therefore we would welcome an underlying principle to support the importance of timely decision-making and streamlined transparent mechanisms for policy development (to be followed through by action) and a process put in place for temporary patient access to medicines that is separate to the IFR process.

Question 3

Do you have any comments on the proposed process for making investment decisions about specialised services?

The process of prioritisation as set out in clause 20 makes sense.

Reference Clause 21 ‘The Cancer Drugs Fund currently remains outside these arrangements.’

PID UK welcomes this commitment but would be extremely concerned if the Cancer Drugs Fund were to become a part of these arrangements, as this would seriously dilute the resources available for very many other rare complex conditions.

Clause 22 covering the five stages of process and practice

Whilst PID UK’s welcomes the setting out of the stages it is important for NHS England to establish timelines for each. Completion of the process must be followed by swift implementation of policy after the process is complete.

PID UK supports the Specialised HealthCare Alliance’s streamlined proposals for improving NHS England’s Policy Development Process as sent as an appendix to their submission to this consultation.

Question 4

Are there any additional stages in the process that we should consider introducing?

There urgently needs to be a principle and mechanism for right to appeal.

Question 5

Are there any additional stages in the process, in addition to those described, where engagement with patients and the public should take place?

Patients and the public are at the receiving end of NHS services and they know what outcomes are important to them. As such PID UK would like to see a process of co-design throughout the process of policy development.

PID UK would like to see an annual stakeholder engagement event for each of the five Programmes of Care where NHS England reports back on progress. This would improve transparency and accountability.

Question 6

Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the principles and process that we have described.

Equity of access to medicine is a fundamental principle and especially important to patients with rare conditions. PID UK does not have any comments on this other than we presume that NHS England reviews all its principles and processes to ensure they do not inviolate this principle.

See also our response to question 7 below.

Question 7.

Are there any other considerations that you think we should take into account when developing the principles and process about investing in specialised services?

PID UK would like to see a principle to cover those occasions when there is urgency and severity of patient need for access to medicines with systems and processes in place that improve and speed up decision making in those circumstances. Services across the UK vary in their staffing and facilities, largely due to the outturn budget approach to funding. Future service provision should rebase budgets, basing this on the service specification as set out in the accreditation process for specialist immunology services.

Question 8

As well as hearing your views on which treatments and services NHS England should prioritise for investment, we are also keen to hear your views on NHS England's rolling programme of service reviews on how specialised services are delivered. If you have any views on which services should be prioritised for a service review in 2015/16, please tell us:

Transition services. Young people with PID and other complex conditions need to have in place robust services and guidance in place to ensure that this vital transfer of care from paediatric to adult goes smoothly.

A recent report by the Care Quality Commission "From the Pond to the Sea" ([link https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf)) has reported over 40,000 children and young people have complex medical needs but only 50% of young people and their parents said they had received support from a lead professional during the process leading up to transition to adult services. The report indicates that young people and families are sometimes confused and at times distressed by the lack of information, support, and services available to meet their complex health needs.

PID UK would welcome the implementation of E03 Paediatric medicine – 'Generic Transition for children and young people to adult services' service specification and incorporation into all relevant service specifications. This would have a huge impact on the health and well being of young people by enabling them to take better responsibility for their condition and improve equity across all services.

Dated 27th April 2015